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The U.S. Department of Health and Human Services defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”. One of the antecedents of health literacy, patient empowerment, has seen an increase from the participation of patients in online health communities. In this study, 4367 group forum posts from 215 users of Anxiety Connect, a moderated online health community, were analyzed using the patient empowerment processes and outcomes of Bartlett and Coulson. Patient empowerment was evident in the forum posts. Every post contained evidence of at least one empowerment process; X% of the posts contained evidence of at least one empowerment outcome. The empowerment process most prominent in the Anxiety Connect forum was *sharing experiences*, included in 57.6% of Total Posts. The empowerment outcome most prominent was *increased acceptance*, included in 5.1% of Total Posts, closely followed by *optimism and hope for the future* and *increased social well-being*, included in 4.5% and 4.7% of the Total Posts respectively. These findings have implications for the design of moderated online health communities.

Headings:

Social media

Mental health

Health literacy

Disclosure of information

Patient empowerment

# FORMS OF PATIENT EMPOWERMENT IN AN ANXIETY DISCUSSION FORUM

by  
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# Introduction

Health is defined by the U.S. Department of Health and Human Services as the “state of physical, mental, and social well-being and not merely the absence of disease and infirmity” (p. 7-28). This definition encompasses a broader viewpoint for the American population than being free of obvious signs of disease or ill health. The status of human health affects the quality of everyday life.

American adults constantly make decisions that affect their health in everyday, health situations. However, use of health information is difficult unless health literacy is adequate. Health literacy is defined in *Healthy People 2010* by the U.S. Department of Health and Human Services as the “degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (p. 7-28). Nine out of ten adults have difficulty using the health information made available to them and the U.S. Department of Education states the percentage of adults in the United States with proficient health literacy is as low as 12% (Rudd, Anderson, Oppenheimer, & Nath, 2007; Kutner, Greenberg, Jin, & Paulsen, 2006, p. 10). Even well-educated adults can face health literacy challenges. These can include a lack of familiarity with medical terms or anatomy, uncertainty when interpreting numbers or risks when making a healthcare decision, and feeling scared or confused upon diagnosis with a serious illness or upon facing complex conditions that require complicated self-care (U.S. Department of Health and Human Services, 2008).

In the 2003 National Assessment of Adult Literacy only 12% of American adults were considered proficient in health literacy and 35% of American adults had either basic or below basic health literacy (U.S. Department of Health and Human Services, 2008). In the latest assessment conducted in 2011-2012, the Program for the International Assessment of Adult Competencies (PIAAC), 12% of American adults performed at the highest level of proficiency (Levels 4/5) for literacy on the PIAAC scale and 9% on the numeracy scale, and this percentage dropped to 6% on the problem solving PIAAC scale (Goodman, 2013, p. 5). American adults who had excellent health performed much higher on the PIAAC scale for problem-solving in technology-rich environments than their peers who self-reported having fair, poor, or good health (p. 6). Health literacy is particularly important to the delivery of “cost-effective, safe, and high-quality health services” as discussed by the U.S. Department of Health and Human Services (2010) in the *National Action Plan to Improve Health Literacy* (p. 3). Additionally, Angel Gurría, Secretary General of the Organisation for Economic Co-operation and Development (OECD), stated that those with “low skills proficiency face a greater risk of economic disadvantage, a higher likelihood of unemployment, and poor health” (2013, p. 3). With better health literacy comes more effective use of health information by the individual, more cost-effective health services and, eventually, improved health outcomes to the patient (U.S. Department of Health and Human Services, 2010).

Traditional healthcare approaches, such as accessing health information solely through a healthcare physician, have lessened due to both rising healthcare costs, estimated to be between \$1.6 trillion and \$3.6 trillion annually, and increasing access to

health information available on the Internet (Huber, Shapiro, & Gallipsy, 2012; Hordern et al., 2011). Internet access is more common and the barrier to access has been lowered due to advances in technology. There is a lot of information available online and many benefits to seeking health information online, but there is also concern about potential misinformation (Hordern et al., 2011). According to the Pew Research Center's Internet and American Life Project, one in three American adults have gone online to figure out a medical condition that they or someone else they know may have (Fox & Duggan, 2013). Seventy percent of U.S. adults got their information or support from medical professionals when they last had a serious health issue, 60% from friends or family, and 24% from others who have the same health condition. Peer-to-peer support remains a strong part of health information exchanges whether online or offline (Fox & Duggan, 2013).

Trends in recent years include searching for health information from other people on social media and in online communities, often termed online health communities. Individuals use online health communities for both information support and emotional support from peers (Preece, 2000). These online health communities often have a role of a moderator who can affect personal empowerment, a factor influencing health literacy. Personal empowerment is often called patient empowerment when it comes to health. The terms are often used interchangeably but refer to the same concept (Johnston, et al., 2013, Mancuso, 2008).

Chronic diseases are defined as "long-lasting conditions that usually can be controlled but not cured" (Center for Managing Chronic Diseases, University of Michigan, 2016). According to the Centers for Disease Control and Prevention (CDC,

2015), chronic diseases are responsible for 7 out of 10 deaths each year, and treating people with chronic diseases accounts for 86% of the United States' health care costs. Chronic diseases require more than an annual doctor's visit and involve a lot of self-management by the patient. According to Aujoulat, d'Hoore, and Deccache (2007), "being chronically ill is a total experience influencing all facets of life" (p. 13). Online health communities provide information and emotional support while not costing any money to the participant and have the benefit of lacking geographic boundaries due to their online format (van Uden-Kraan et al., 2009).

Stress has a strong, negative influence on health in the United States. The American Psychological Association started a nationwide survey conducted by Harris Poll asking Americans questions about their stress and factors of their stress. Using data from 2007 to 2015, they found that high levels of stress have profound effects on health and longevity. They also found that the top four stressors of Americans are money, work, family, and health concerns, and that these stressors are easier to cope with and better managed when the individuals have emotional support (Anderson et al., 2015).

Anxiety, a subset of mental health and also a chronic illness, requires self-management techniques. There is a prevalence of stress and anxiety in the American population, as shown by Anderson et al. (2015). For this research study, the online forums of an online health community will be studied to look for the presence of patient empowerment. The online forum to be studied is focused around anxiety as a major chronic illness that affects our health. Americans and other global patients reach out to these online health communities for both health information and emotional support that cannot be attained from a singular doctor's visit. Through this process of informational



and emotional exchange, patient empowerment can occur and theoretically leads to greater health literacy, as patient empowerment is a factor in health literacy. Moderation has been seen in the literature to lead to increased patient empowerment due to a decrease in potential negative factors, so the focus of the study will be moderated forums.

# Literature Review

The pertinent literature is divided into sections on health literacy, online health communities and patient empowerment in online communities.

## Health Literacy

### Basic Literacy

Before addressing the question of health literacy, the question, ‘what is basic literacy?’ must be addressed first. The most basic literacy is the ability to read and write. In 1991, the National Institute for Literacy expanded the definition to mean “an individual’s ability to read, write, and speak in English and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and to develop one’s knowledge and potential” (p. 7). In the International Adult Literacy Survey, literacy is defined as a constellation of skills including reading, writing, basic mathematical calculations, and speech and speech comprehension skills (Kirsch, 2001). The Centre for Literacy of Quebec defined literacy in 1989 (revised in 2014) as “a complex set of abilities needed to understand and use the dominant symbol systems of a culture for personal and community development” (Centre for Literacy, 2014). Kindig, Panser and Nielsen-Bohlman (2004) broke literacy down into multiple components of oral literacy, print literacy, and functional literacy in his interpretation of National Assessment of Adult Literacy. From these early definitions, one can see that the concept of literacy has changed over time to

encompass more than just the ability to read and write, but also to include information processing and to recognize the context of culture, language, etc.

From 1 August 2011 to 31 March 2012 the OECD Programme for the International Assessment of Adult Competencies (PIAAC) conducted its first Survey of Adult Skills in 22 OECD member countries and 2 partner countries, including the United States. The target population was adults aged 16 to 65, with 166,000 adults surveyed, and the goal was to assess and compare the basic skills and competencies necessary to function in the 21st century (OECD, 2013; Goodman, 2013). These assessments of skills include literacy, numeracy and problem solving. These three are defined as follows,

“Literacy: the ability to understand, evaluate, use and engage with written texts to participate in society, achieve one’s goals, and develop one’s knowledge and potential.

Numeracy: the ability to access, use, interpret and communicate mathematical information and ideas in order to engage in and manage the mathematical demands of a range of situations in adult life.

Problem solving in technology-rich environments: the ability to use digital technology, communication tools and networks to acquire and evaluate information, communicate with others and perform practical tasks” (OECD, 2013, p. 4).

The PIAAC uses five proficiency levels for literacy and numeracy (Below level 1, Level 1, Level 2, Level 3, and Level 4/5) and four levels for problem solving (Below level 1, Level 1, Level 2, and Level 3) (Goodman 2013). In all but one participating country, at least one in ten adults was found to be proficient only at or below Level 1 in literacy or numeracy, which are the most basic information-processing skills needed to succeed in the modern world (OECD, 2013). In the United States, 4% of adults were Below level 1, 14% were Level 1, 34% were Level 2, 36% were Level 3, and 12% were Level 4/5 for the literacy assessment (Goodman, 2013, p. 10). Only 2% of American adults were actually level 5 for literacy. In the United States, 10% of adults were Below level 1, 20%

were Level 1, 34% were Level 2, 27% were Level 3, and 9% were Level 4/5 for the numeracy assessment (p. 11). In the United States, 20% of adults were below level 1, 41% were Level 1, 33% were Level 2, and 6% were Level 3 for the assessment of problem solving in technology-rich environments (p. 12).

## **Health Literacy**

Health literacy is more complicated than basic literacy. An individual could be considered literate but not adequately health literate at the same time. This is why the consideration of the many components of health literacy is important (Huber, Shapiro, & Gallipsy, 2012). ‘Health literacy’ was first used as a term by Simonds (1974) in a paper about health education as a means of social change. The Joint Committee on National Health Education Standards (1995) defined health literacy as “the capacity of individuals to obtain, interpret and understand basic health information and services and the competence to use such information and services in ways which enhance health” (p. 5). In 1999, the Ad Hoc Committee on Health Literacy of the American Medical Association defined health literacy as a “constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the healthcare environment”, and everyday health functions were further defined as the “ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials” (p. 553). These two early definitions can be seen in the later definition included in *Healthy People 2010*: “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (U.S. Department of Health and Human Services, 2000, p.7-28). The Partnership for Clear Health Communication Steering Committee (2007) defines health

literacy “simply as the ability to read, understand, and act on health information” and states a correlation between low reading skill and poor health (p. 2). These definitions have their limitations but health literacy is the bridge between the literacy skills and abilities of the individual and the specific health context. *Healthy People 2020* built upon the earlier work of *Healthy People 2010* and previous editions. One of the objectives of *Healthy People 2020* is to “Improve the health literacy of the population” (Committee on Leading Health Indicators for Healthy People, 2011, p. 31).

Mancuso (2008) elaborates on the concept of health literacy by looking at all aspects, including the antecedents, attributes, and consequences of health literacy, to form a multidimensional definition. The antecedents are the skills and abilities of the individual patient in relation to health literacy and include operational, interactive, autonomous, informational, contextual, and cultural skills and abilities. Operational competence is the ability to meet everyday basic health needs by utilizing tools, procedures, and techniques for handling language proficiently. Interactive competence is the ability of the patient to collaborate with others for individual improvement and enhancement through self-management, which includes decisions and actions taken by the individual to improve health. Autonomous competence, also known as personal empowerment, is the self-awareness that aids the patient to effectively assume responsibility for health-related decisions and thus be able to judge and use information in the context of one’s own life, resulting in greater control over health. Informational competence is the ability to determine the authority and the currency of health information. Contextual competence is the mastery of the healthcare environment by the

patient. Cultural competence is the ability to interpret the meaning system of social practices (Mancuso, 2008).

The attributes of health literacy (i.e., the components that make up the patient's level of health literacy) are capacity, comprehension, and communication. Capacity is the innate potential of the individual in health literacy. Comprehension is the process of the interaction of logic, language, and experience necessary to accurately interpret information. Communication is how the thoughts, messages, or information are exchanged, particularly important in the health environment. The consequences of inadequate health literacy, discussed in further depth later, are far-reaching and include greater health-care costs, less knowledge of their disease or illness, fewer self-management skills, medication errors, poor compliance, etc. (Mancuso, 2008).

### **Consequences of Inadequate Health Literacy**

Health literacy is a recognized problem in the U.S. and is why, in an era of increasing healthcare costs, the health literacy movement was constructed top down by policy makers at the top. The 2012 estimate of the cost of limited health literacy was between \$1.6 trillion and \$3.6 trillion annually with future costs included. The cost to the economy annually was estimated to be between \$106 billion and \$236 billion. The focus on health literacy was an attempt to address more effective healthcare delivery, healthcare cost containment, and improved health outcomes of patients (Huber, Shapiro, & Gallipsy, 2012). Inadequate health literacy is often associated with poor health status. Berkman (2004) reports low literacy as being associated with a "poor understanding of written or spoken medical advice, adverse health outcomes, and negative effects on the health of the population" (p. 1). Mancuso (2008) further specifies that those with

inadequate health literacy have “increased health-care costs, less knowledge of their diseases and treatments, fewer self-management skills, less ability to care for chronic conditions, poor compliance, more medical or medication treatment errors, a lack of the skills needed to successfully negotiate the health-care system, and less access to health-care” (p. 51).

Costs of inadequate health literacy may include economic costs to society and the healthcare system as well as costs of humans in relation to disease. There is a relationship between hospitalization rates and inadequate health literacy. Those with inadequate health literacy are significantly more likely to have been hospitalized, according to Kindig, Panser, and Nielsen-Bohlman (2004), and thus have higher hospitalization or emergency services’ healthcare costs. Those with inadequate health literacy also self-report as having poor or worse health status compared to those with adequate health literacy. They are also associated with a lower use of preventative health services such as getting the influenza and pneumococcal vaccinations, mammograms, or Pap smears. Preventative health services keep healthcare costs lower. However, many adults overestimate their knowledge and understanding of health information and thus their own health literacy. If they do realize their poor health literacy, they may feel shame. Both are barriers to improving the health literacy of U.S. adults (2004).

### **Health Literacy Movement**

The health literacy movement started in the 1970s with the realization that if individuals understood more about their bodies and their healthcare, they would take more preventative measures to keep them out of hospitals and physicians’ offices.

Interest in this movement from the top waxed and waned. Concurrently in the 1960s and beyond, the consumer health movement demanded more access to health information.

The previously passive patient at the bottom of the system began to take a more active role in the healthcare environment, but even as this access to information increased throughout the decades, the barrier of low literacy and low health literacy remained.

Throughout the last decades of the 20<sup>th</sup> century, the healthcare system has become more complicated and requires a higher education level to access it in meaningful ways according to Huber, Shapiro, and Gallipsy (2012). For several decades the U.S.

Department of Health and Human Services has been concerned with the health literacy of the population and one of the objectives of *Healthy People 2020*, the latest edition, is to “improve the health literacy of the population” (Committee on Leading Health Indicators, 2011, p. 31). The consumer health movement focused on providing access to health information, but the ultimate goal of the consumer health movement requires these same consumers to be health literate (Huber, Shapiro, & Gallipsy, 2012). Nutbeam (2005) posits that health literacy is critical to empowerment and that the ultimate goal for health literacy is “to promote greater independence and empowerment among the individuals and communities” (p. 267). Individuals who actively seek health information are empowered by their acquisition of knowledge (Huber, Shapiro, & Gallipsy, 2012)

## **Online Health Communities**

### **Online Communities**

Online communities are used for many Internet social interactions. ‘Online communities’ are online social gatherings and ‘online communities’ is a term coined by Rheingold (1994). Rheingold described early online communities as “cultural



aggregations that emerge when enough people bump into each other often enough in cyberspace” (Rheingold, 1994, p. 57). Dosani, Harding, and Wilson (2014) have a similar definition of online communities, seen as simply the digital or online medium allowing members to interact with one another using the Internet. Members may also have to ‘sign up’ and be expected to abide by certain rules and behaviors to interact as a part of the community, whether it is by forums, chat rooms, or subscribing to email lists. Barak (2008) lists the forums as the overriding technology and clear choice for their asynchronicity, easy access, opportunity for archival search, use of emoticons and links, and user-friendly design. Preece (2000) is an authoritative, early source on online communities. Her working definition of an online community consists of four components: people, a shared purpose, policies, and computer systems. These components all form together to influence social interaction in the community. These criteria are also stated as “the collective purpose of a community, the goals and roles of the individuals in a community, and policies generated to shape social interaction” (p. 7). Dosani, Harding, and Wilson (2014) also list similar characteristics of an online community. These include virtuality, shared goals, media richness, a support network, lack of physical co-location, computer connection, more openness to talking, and relief from telling anecdotal stories and the support they feel.

Agnew (2001) looks at the positive and negative attributes of online communities. Some of the positive ones include convenience and accessibility of the groups, that typing out feelings online in itself is therapeutic, a frequent exchange of resources and information, a shared interest rather than shared social characteristics, and the ability to be anonymous. Some of the negative attributes include the questionable value of

information, that individuals' privacy may be at greater risk, that non-verbal cues are lost in typed conversations, and that participants must have access to a computer and the Internet to access the online communities (2001). Online communities are designed to foster many psychological factors including well-being, a sense of control, self-confidence, feelings of more independence, social interactions, and improved feelings. Barak (2008) states the overall purpose of online communities focused on support is to offer relief and improved feelings for the participants. A few of the negative factors include developing dependence, distancing from in-person contacts, and exposure to unpleasant experiences online. Many online communities may operate largely without a professional leader or administrator and, as open forums, participants can come and go at any point, leading to a constantly fluctuating population.

The common thread in online communities, versus other information found online, is the human connection. Online communities need people; without participants there would be no community. Each person has a different reason for joining the community; they have different goals and different needs to satisfy. However they need to have an overall, collective purpose or the community and the discussion will not be successful (Preece, 2000). The community policies help with this shared purpose. If the community purpose and related policies are clearly stated, it will attract participants with relatively similar needs for its membership and will help with the ease of conversation in regards to sociability. The computer systems are concerned with usability in that they are pleasant and effective to use for participants, so that they keep coming back. Some communities endure over time and some are here today and gone tomorrow (Preece, 2000).

## **Online Health Communities**

Preece (2000) also explored the beginning of online health communities. The general public began to go online to find information for a health-related problem as health information became more accessible online in the mid to late 1990s. They would want to find information about diseases and treatments and to understand their individual problem better but also to get emotional and informational support from others and to reciprocate for others who were suffering in a health manner (2000). From the consumer perspective, the Internet offers almost limitless health information, with multiple perspectives, and the ability to communicate with others when a health care provider would not be available (Willis, Yang, & Rodgers, 2012). In the Health Online 2013 report, one in three American adults have gone online to figure out a medical condition that they or someone else they know may have and the peer-to-peer support remains a strong part of this (Fox & Duggan, 2013). With the use of the Internet, health information is easier to access than ever. Patients can quickly connect with vast content, the up-to-date information, and expertise. Patients and health care professionals potentially have access to the same healthcare information and guidelines through the tool of the Internet and proponents argue that this has “the capability to improve patient care, and provide efficiency, ease of access, and savings” (Gurak & Hudson, 2006, p. 31).

Online health communities are a specialized subset of online communities (Johnston et al., 2013). van der Eijk et al. (2013) studied the use of online health communities as a tool for future generations to generate high-quality and affordable healthcare. Online health communities are an Internet-based platform that unites a group of patients, a group of professionals or a mix of both and they interact using blogs, chats, forums or wikis. Online health communities can be used to share personal experiences,

exchange pertinent knowledge, and increase disease-specific expertise. Online health communities also can bridge geographical distance to connect more people together and can be used to empower patients to self-manage their diseases (2013). In other words, online health communities share many similarities with online communities as a format but are focused on a specific health topic. Patients can also receive information plus support from online health communities, and sharing with other patients may support needs that physicians cannot. Similarly websites can offer health information but lack the human connection of support or more personal resources. Face to face health communities may be available in these cases, but involve matching a patient's time and place to the convenience of the physical community. Online health communities allow patients to share experiences with one another and relate to each other's problems whenever time of day or night and wherever they may be geographically. However, one potential downfall of online health communities that physicians are concerned about is the potential for misinformation passed back and forth among patients (Preece, 2000).

Beaudoin (2007) conducted an online survey of cancer patients and found positive health outcomes in terms of stress, depression, and coping. This was from a method of asynchronous online communication on the part of the patients, which lead to social interaction, then social support, and then the positive health outcomes.

### **Moderators in Online Communities and Online Health Communities**

Moderators and mediators help to govern communities. These roles vary according to the policies of the specific community but Preece explains how they both try to ensure that people behave reasonably and help to guide activity in the community. The distinction between moderators and mediators is that mediators are generally called in to

settle disputes, while moderators are more heavily involved in the community (Preece, 2000). There is the human element in online communities and they often have an open, honest, and intimate nature. With these can come aggressive and unpleasant attacks; moderators try to prevent these attacks as well as spam. Other tasks can include facilitating, managing the list, filtering messages, being the expert, editing messages, opening questions to generate discussion, marketing the list to others, and helping people with general needs. However keeping out flaming and attacks are high on the list of moderator tasks as they can be devastating, particularly in online health communities (Preece, 2000).

A number of studies have investigated the role of moderators in online communities. Edwards (2002) looked at the role of the moderator in five Dutch Internet discussions about public issues. In these discussions the moderators were independent third party moderators with importance placed on transparency and negotiability of moderation. The common view of the role of the moderator in Internet discussions is that the moderator is a filter, but in this study the filter function of moderation appeared to be of minor importance. Moderators did have a lot of other functions such as contribution to the interactivity and openness of discussions and the accessibility of the community topic. Berge (2000) reports on a probabilistic survey about list moderators' perceived roles, responsibilities and tasks. These included filter, firefighter, helper, facilitator, editor, discussion leader, manager, content expert, helper, and marketer. Reported reasons for moderation were keeping the signal to noise ratio high, keeping the discussion focused on the topic, keeping down 'flames' or negative posts, and digesting/editing posts. Dosani (2014) studied an online mental health forum, the Big White Wall, that can

be highly triggering to patients if not moderated. The moderators focused on negating negative interactions to avoid negative outcomes for its users. Huh et al. (2013) analyzed 480 patient and moderator posts from six communities to better understand how moderators fulfill patients' information needs. Patients used the community as an integral part of their health management practices and moderators played a unique role in supporting patient care. Huh also addressed monitoring and the discouraging of asking clinical questions in the community by moderators. Huh et al. (2015) examined posts where moderators redirected patients to see their health care providers instead of consulting the community. Huh found that community members provided constructive tips and persuaded patients to see doctors, but moderators' posts were associated with no more follow up replies or essentially ending the conversation in the community. Bartlett and Coulson (2011) surveyed 33 patient moderators using an online questionnaire with a series of open-ended questions. Three thematic themes included emergence, empowerment and nurturing, and moderators described needing to nurture their group and to make it a safe space for members of the community. Essential elements included clear rules of engagement, trust, organization skills, compassion and kindness (2013). Matzat and Rooks (2014) studied the acceptance and effectiveness of different moderation styles. Matzat used two experimental scenario studies and results showed that direct forms of control were not accepted and were regarded as ineffective. More indirect forms such as those that rely on relational interests and normative obligations, were more accepted and considered more effective. Positive or rewarding moderation styles were also more effective than negative or punishing styles. Negative moderation styles were seen as most effective for avoiding rule-breaking or unacceptable behavior in

the online health community. Lander (2015) studied moderators' strategies using a discourse analytical approach informed by systemic functional linguistics. Moderator strategies supported online learning communities. Highlights of moderator strategies include that interpersonal strategies are implicit and muted, instructions are downplayed and opportunities for divergent views are maximized. Wise, Hamman, and Thorson (2006) compared how moderation, response rate, and message interactivity affected people's intent to participate in an online community, comparing one moderated community and one unmoderated community. Sixty-two participants observed one or the other and were asked questions about their intent to participate afterwards. Wise, Hamman, and Thorson found that people were more likely to participate in a moderated community than an unmoderated community. Lindsay, Smith, Bellaby, and Baker (2009) conducted a study to assess whether an online closed heart care support group and accompanying information resource would have any changes with the withdrawal of moderator support. In the randomized control trial half of the patients with heart problems received access to the password-protected site and half did not. After the first three months, the online health community was no longer moderated and the same group had significantly more healthcare visits than the control group.

These studies all found moderator roles to vary greatly. Wise, Hamman, and Thorson (2006) found patients were more likely to participate in a moderated community and Lindsey, Smith, Bellaby, and Baker (2009) found that patients were more likely to see a positive health outcome from a moderated community versus an unmoderated community. One of the common roles of the moderator was as a filter, as well as to contribute to interactivity and discussions in the community (Edwards 2002; Berge 2000;

Dosani 2014). Bartlett and Coulson (2011) reiterated that the moderator was to help keep the community a safe space for nurturing and learning. However, Huh (2015) found that too much moderator interaction can stop the conversation occurring in the community. Similarly Matzat and Rooks (2014) found that a moderation style that was too direct was not effective and both they and Lander (2015) recommended a less direct and more implicated and muted approach on the part of a moderator.

## **Patient Empowerment**

### **Patient Compliance**

The role of the patient in healthcare is often considered in terms of compliance or empowerment. According to Wentzer and Bygholm (2013), patient compliance is whether the patient adheres to the recommendations of the medical authorities or the extent to which their behavior complies with medical advice. The term compliance was coined in the 1970s and in more recent years the preferred term has swayed towards adherence. Compliance implies behavioral characteristics of the individual are at fault in not complying, while adherence takes into account behavioral attitudes and the patient's social and economic situational factors. Both imply treatment problems are the fault of the patient for not complying or adhering to the doctor's prescribed regimen.

The compliance approach is the traditional approach and aligns with the traditional doctor-patient relationship (2013). This approach has an emphasis on learning and skills that are needed to carry out the prescribed healthcare regimen and the recommendations made by the health care professionals. According to Feste and Anderson (1995) the traditional compliance approach to healthcare would reduce patient



autonomy and constrain a patient's freedom of choice, while an empowerment-oriented approach increases patient autonomy and expands freedom of choice.

## **Patient Empowerment**

In early literature patient empowerment was defined by its opposite such as alienation, victim-blaming, learned helplessness or powerlessness. Instead Wallerstein and Bernstein (1988), early authorities on empowerment, defined empowerment “as a social action process that promotes participation of people, organizations, and communities in gaining control over their lives in their community and larger society” (p. 380). Another early source on empowerment, Rappaport (1987) defined empowerment as a process “by which people, organizations, and communities gain mastery over their affairs” (p. 122). Empowerment for individuals is a very personal outcome and includes the ability to make personal decisions, to exercise critical thinking, and to access relevant resources (Wallerstein, 1992). Empowerment also refers to “experiencing personal growth as a result of developing skills and abilities along with a more positive self-definition” (Staples, 1990, p. 29) and “an individual's inherent capacity to be responsible for their own life” (Wentzer & Bygholm, 2013, p. e387). Feste and Anderson (1995) discuss an educational empowerment approach “to help patients develop the knowledge, skills, attitudes and degree of self-awareness necessary to effectively assume responsibility for their health-related decisions” (p. 139) and argue that such education leads to a more autonomous empowerment outcome. Empowerment is not specific to a disease or treatment but can affect all of an individual's health decisions. Rather than being seen only as the recipients of medical decisions and prescriptions, the empowerment approach views patients as being involved in their decisions and

responsible for their choices and the consequences of their choices (Aujoulat, d'Hoore, & Deccache, 2007).

Personal empowerment is also one of Mancuso's (2008) antecedents of health literacy. "Autonomous competence is personal empowerment" (p. 249). Personal empowerment is defined as a self-awareness that helps the individual in assuming responsibility for their healthcare-related decisions. Ultimately, the individual takes greater control over their own health situations and grows in their ability to take action to change factors of their environment that might affect their health. Personal empowerment as an antecedent of health literacy also links it to the improved health outcomes of a higher health literacy (Mancuso, 2008).

Online health communities can be leveraged to promote both the health and well-being of the participants (Johnston et al., 2013). Aujoulat et al. (2007) looked at some of the health outcomes from empowerment in online health communities with patients with chronic diseases. These health outcomes were most frequently found to relate to the patient's disease and its treatment, the patient's self-determination of health and treatment-related goals made through participation and negotiation, and the patient's increased self-efficacy regarding their disease and treatment-related behaviors. Other outcomes included enhanced knowledge regarding the patient's disease and treatment, an enhanced quality of life as a result, an enhanced capacity to deal with negative feelings about the patient's disease and healthcare situation, a personal transformation of the patient's self in relation to their environment, and a better psychosocial adaptation in regards to a capacity to resume life activities sooner. Nonspecific outcomes of the

patient's empowerment included decision and implementation of behavior changes, enhanced control, personal satisfaction, and responsibility (2007).

### **Patient Empowerment Through Online Health Communities**

A number of studies have investigated the effects of online community participation that may foster patient empowerment. Johnston et al. (2013) looked at how patient empowerment outcomes were gained through participation in online health communities by surveying 153 patients from 18 online health communities. The two main factors suggested were the exchanging of information allowing for a collective wisdom among the community, which can be adopted for personal benefit, and the emotional support and self-development allowed by the informal online community support structure. These unique benefits often exist solely in the online health community. Thus information utility and social support of the online health community may ultimately lead to patient empowerment. The amount of participation in the online health community can also affect how much information utility and social support the patient is receiving and therefore also the level of patient empowerment. Willis (2014) looked at the information utility aspect as a part of the self-management program of the online health community. The self-management behaviors were encouraged in the online health community by the exchange of health information and disease experience. The health literacies of the online health community members were ultimately improved. Santana et al.'s (2011) investigation into patient use of the Internet for health information agreed with the positive view of online health communities for patient empowerment. More inquisitive and autonomous, 'empowered' patients were seen with greater participation in online health communities. Bartlett and Coulson (2011) also found

evidence of the empowerment processes and outcomes present in online health communities from an online questionnaire with 246 participants across 33 online health communities. The empowerment processes are indicators that patient empowerment is occurring. The outcomes included “feeling more informed, increased confidence with physician, increased acceptance of illness, increased confidence in treatment, increased optimism and hope for the future, enhanced self-esteem, enhanced social well-being” (p. 116). The majority of the study participants had discussed this information found online with their healthcare professionals. Similarly the earlier study that Barlett and Coulson drew from, van Uden-Kran et al. (2009), found empowerment from participating in online health communities. The 528 participants felt empowered by ‘being better informed’ and ‘enhanced social well-being’. van Uden-Kraan et al. concluded that participation in online support groups can contribute to the empowerment of patients. Barak, Boniel-Nissim, and Suler (2008) found that other possible generators of “personal empowerment” are the impact of writing, expressions of emotions, collecting information and relatedly improving understanding and knowledge, developing social relationships, and enhancing decision-making skills and behavioral actions. All of these were accelerated by an online disinhibiting effect. Mo and Coulson (2014) added additional generators on empowering and disempowering processes including exchanging information, sharing experiences, connecting to others, encountering emotional support, finding recognition and understanding, and helping others. Six empowering outcomes that they identified were increased optimism, emotional well-being, social well-being, being better informed, improved disease management, and feeling confident in the relationship with physicians. Mo and Coulson (2010, 2013) had two previous studies

where they also looked at patient empowerment in online health communities. In the first study (Mo & Coulson, 2010) with 340 individuals, they measured satisfaction with online support groups, empowering processes, self-care self-efficacy, loneliness, optimism, coping, depression, and health-related quality of life. The measures of satisfaction showed that lurkers, who only read the posts and do not interact directly with others, scored lower in social support, useful information, and satisfaction with group members, but showed no significant differences in self-care efficacy, loneliness, depression or optimism compared to posters. The second study (Mo & Coulson, 2013) again surveyed 340 online health community users and showed that higher levels of online health community participation had higher levels of empowerment and better psychological health. Their studies highlighted the lurker who may be empowered but also will not show up in certain types of studies. Their results also suggest that the interaction in the online health communities is a large part of the empowerment process to get to the empowerment outcomes. Petrovčič and Petrič (2014) also showed similar results from a nonprobability sample of 616 users of online health communities. They found that posters scored higher in empowerment when it came to interacting but did not show a difference in intrapersonal empowerment.

### **Moderators and Patient Empowerment in Online Health Communities**

Online health communities in particular support the development of patient empowerment in participants by creating and disseminating information to further the understanding of a patient's health condition. Implications for moderators include ensuring a high level of engagement among the participants to allow information utility to occur and also guarding against potential undesirable circumstances that could negate a

positive experience. Information utility and social support are part of what raises the level of patient empowerment but the moderator plays a large role in encouraging those two effects (Johnston et al., 2013).

## Methods

The research question being explored in this study is, “How is patient empowerment expressed in a moderated online forum of an online health community?” This study is focused on analyzing data from forum posts in an online health community centered on anxiety. A sample of 4367 forum posts of repeat, multiple users were coded for patient empowerment processes and outcomes using Bartlett and Coulson’s coding scheme (see Appendix I Coding Manual).

### Sample Selection

Several online health communities that were moderated were considered for inclusion in this study. Ultimately the online health community needed to have a forum post section that was open to the public with or without a login and to have terms of service that were amenable to academic research. The online health communities that were considered also were focused around the mental health topic of anxiety. Anxiety Connect, an online health community of the large Alliance Health community, fit these criteria, and responded favorably with the emailing of one of the moderators, Abbey Crandall, from January 20<sup>th</sup> to January 28<sup>th</sup> 2016. The community moderators are called community managers or advocates for Anxiety Connect. More information was requested about the project and upon receipt of the information permission was given by the moderators to proceed with use of the forum posts for this research.

Anxiety Connect is an online health community specifically focused on helping people who suffer with anxiety. As mentioned before, it is a small part of the larger community, Alliance Health and the Social Networks for Health Conditions. Alliance Health has more than 25 social networks with more than 1.5 million registered members. The goals for all of the communities include connecting patients to patients, tracking important health data, providing reminders, and helping patients save money on healthcare costs. All of this aims to help consumers more actively manage their care in their chronic illness (Alliance Health, 2016). The structure of Anxiety Connect includes discussions, news articles, product reviews, and videos. This information is largely viewable without joining or registering for the community. Nonetheless registration is encouraged for more active participation and extra features such as private messaging with other patients or earning ‘badges’ for participation in the site. The discussion section is where the online forums are located. Anxiety Connect is a moderated online community with moderators termed ‘community advocates’ or ‘community managers’ who are available for contact. There are also general guidelines or rules for new members, of which the general and the discussion guidelines are the most relevant.

#### “General Guidelines

Be respectful and kind.

Realize that sarcasm and joking will often be misunderstood.

Typing in ALL CAPS is considered shouting.

Be careful about giving out medical advice—sharing your own experience is fine, but don't tell others what they should do.

Know that abusive or offensive behavior is not tolerated.

#### Discussion Guidelines

Discussions are a great place to interact with and learn from others. Here are a few tips to help you get the most out of your experience in the discussion boards. Discussions with specific titles will receive more responses and better participation.

Ask the community for their experience, advice, or opinion.



Beware of telling others how to use the site—it's better to share any concerns directly with the community managers.  
 Use the discussions for topics of general interest and the inbox for private conversations.”  
 (<http://www.anxietyconnect.com/about#KLX65M4d8SWK1TOo.97>)

The data being accessed on Anxiety Connect is composed of individual posts on the Anxiety Connect group discussion forum. The group discussion forum on Anxiety Connect is made up of multiple conversations in the form of individual posts. For this study the individual post is the unit of analysis. The data being accessed was posted between 1 January 2014 and 31 March 2014. The target timeframe was chosen for several reasons. First, three months of individual posts seemed sufficiently numerous for the purposes of this study. Second, the beginning of the year was chosen with New Year's and New Year's resolutions in mind. It seemed likely that the target timeframe would be more active in posting due to the essence of New Year's resolutions, self-help resolutions of change for the better and actions for the New Year. Third, the year 2014 was chosen rather than 2015 due to the lower level of individual posting activity in forum posts in 2015 in general. In the three months of data, there were 932 Main Posts and 3911 Comments, or 4843 Total Posts. This amounts to a little under 5000 individual forum posts in total available before data cleanup.

For research purposes, only repeat, multiple posters were included. Patient empowerment was more likely to be shown in multiple posts and the users who only posted a few times were much closer to the lurker category in the community. This also means anonymous posters were removed as it is unclear whether they were repeat, multiple posters or not. A user must have posted at least five times to count as a repeat, multiple poster. After cleanup, the three-month data had 782 Main Posts and 3585 Comment Posts or 4367 Total Posts.

The forum posts were accessed and scraped with the assistance of Matthew Jansen, a librarian at the University of North Carolina Chapel Hill Walter Royal Davis Library. The forum was manually examined to determine the structure of the URLs, which were found to be the following format:

*http://www.anxietyconnect.com/discussions/<post number>*. The post numbers were chronological and ran from 13951-14989 for the target timeframe. Next, the html underlying each post was manually inspected to identify the structures holding the post text, comment text, usernames, and times. A Python (2.7) script was developed to read the html code for each page in the target timeframe, using the urllib package; to parse the html to find and extract the relevant information, using the BeautifulSoup package; and to structure the data as two tables and export them. The two resulting tables were MainPosts.csv, which contained each main thread post, the post number, the username, and the time of the post and Comments.csv, which contained each reply comment, thread number, username, and time of the post.

## **Coding the Data**

To explore how patient empowerment was presented in the Anxiety Connect group discussion forum, the Bartlett and Coulson (2011) coding scheme was used. Also considered was the coding scheme of Mancuso (2008), which was rejected as too complicated to interpret reliably. Bartlett and Coulson's coding scheme (see Appendix I for the Coding Manual), focused on patient empowerment processes and outcomes, was adapted from an earlier study by van Uden-Kraan et al. (2009). The five patient empowerment processes and the seven outcomes are very similar but the Bartlett and Coulson interpretation was more easily identifiable in a quantifiable form in the forum

posts and thus was a better fit for the current study. The Bartlett and Coulson coding scheme includes both empowerment processes and empowerment outcomes. The empowerment processes include exchanging information, exchanging social support, comparison with other members, helping others, and sharing experiences. The empowerment outcomes include feeling informed, increased confidence with physician, increased acceptance, increased optimism and hope for the future, enhanced self-esteem, enhanced social well-being, and increased confidence in the treatment.

The coding was tested for reliability. One hundred posts were set aside from the Main Posts and 250 posts were set aside from the Comment Posts. The posts were selected by formatting the Excel spreadsheets by time of day so that the individual posts could be any user or any date and the first 100 and first 250 were selected. Once a familiarity was reached with the coding scheme, the investigator and an independent party coded the 350 posts independently. The latter was given a brief training and examples of each of the empowerment processes and outcomes. The reliability data was gathered in Excel with the Processes and Outcomes analyzed as two separate columns, particularly as Processes were found to be much more prevalent than Outcomes. The two sets of coding were reviewed manually with a 1 for agreement or a 0 for nonagreement across all the codes of each type assigned to each post. The Processes had an agreement of 80% with a disagreement of 20% (70 posts). The disagreements were found largely to be confusion over the difference between two of the Processes: exchanging social support and helping others. The disagreements were reconciled through additional review by the author and agreement increased to 90% and disagreement decreased to 10% (35 posts). Half of these used the initial codes assigned by the author and the other used the initial

codes assigned by the second coder. The empowerment outcomes had an agreement of 91.4% and a disagreement of 8.6% (30 posts). The disagreements were reconciled in the same way as for the Processes disagreements; again, half the final codes were initially assigned by the author and half by the second coder. Agreement increased to 95.7% and disagreement decreased to 4.3% (15 posts). Important to note is that there were a lot less Outcomes present and while the two coders were largely in agreement over whether the outcomes were present or not, disagreement was largely over the exact combination of outcomes due to a higher difficulty of interpretation for the outcomes.

### **Analysis of the Codes**

The frequency of occurrence of each of the Processes and Outcomes codes were tallied. In addition, the content of the posts were analyzed qualitatively, to better understand the ways in which empowerment processes and outcomes were expressed in this online forum.

## Results

There were 782 Main Posts and 3585 Comment Posts analyzed, combining for 4367 Total Posts in the three-month set of data (see Table 1). Empowerment processes were present in all of the posts. Empowerment outcomes, however, were present in only 723 of the posts or 16.6% of the data. Often multiple empowerment processes or outcomes were present in a single post, leading to a greater number of processes or outcomes than there were individual posts. For example, there were a total of 7162 empowerment processes compared to 4367 Total Posts and 1113 empowerment outcomes compared to the 723 individual posts that showed empowerment outcomes. The total combined empowerment processes and outcomes were 8275, almost double the amount of individual posts.

**Table 1. Number of posts analyzed**

	<b>Number of posts analyzed</b>	<b>Codes for empowerment processes</b>	<b>Codes for empowerment outcomes</b>	<b>Total codes assigned</b>
Main Posts	782	1353	129	1482
Comments Posts	3585	5809	984	6793
Total Posts/Codes	4367	7162	1113	8275

The empowerment processes were *exchanging information, exchanging social support, comparison with other members, helping others, and sharing experiences*.

The frequency of expression of each empowerment process is reported in Table 2.

*Sharing experiences* was the empowerment process that occurred most frequently, appearing over 2500 times overall, most of which were in Comment Posts. *Comparison with others* and *exchanging support* were also frequently expressed processes in Main Posts, and *exchanging social support* and *exchanging information* were frequently expressed in Comment Posts.

**Table 2. Frequency of expression of empowerment processes**

	Processes in Main Posts		Processes in Comment Posts		Processes in Total Posts	
	n	%	n	%	n	%
Exchanging information	115	8.5%	1005	17.3%	1120	15.6%
Exchanging social support	254	18.8%	1456	4.3%	1710	23.9%
Comparison with others	275	20.3%	819	14.1%	1094	15.3%
Helping others	29	2.1%	694	12.0%	723	10.1%
Sharing experiences	680	50.3%	1835	31.6%	2515	35.1%
TOTAL	1353	100.0%	5809	100.0%	7162	100.0%

Another way to consider the prevalence of each type of empowerment process is by examining the proportion of posts that included an expression of each type. The results of this type of analysis are shown in Table 3. *Sharing experiences* was the empowerment process that occurred most frequently in the both the Main Posts at 87.0% and in 57.6% of all posts. *Exchanging social support* was also expressed in a high proportion of all posts (39.2%), but was slightly more common in Comment Posts than in Main Posts. An analysis by user is shown in Appendix II.

**Table 3. Proportion of posts including expressions of empowerment processes**

	<b>Main posts</b>	<b>Comment Posts</b>	<b>Total Posts</b>
Exchanging information	14.7%	28.0%	25.6%
Exchanging social support	32.5%	40.6%	39.2%
Comparison with others	35.2%	22.8%	25.1%
Helping others	3.7%	19.45	16.6%
Sharing experiences	87.0%	51.2%	57.6%
Total number of posts	782	3585	4367

Note: The percentages are calculated using the frequencies from Table 2 as the numerator and the Total number of posts from this table as the denominator.

*Exchanging information* involved giving or asking for factual information such as general information about anxiety, drug symptoms, treatment information, or articles, books or audio that could be of help to ease anxiety. Examples of this include: “How normal is this? Is it normal for it to last all day?” and “Read the Linden method...He was a sufferer for over 20 years and attempted suicide as well.” *Exchanging social support* involved giving or asking for emotional support. Examples of this include: “Hang in there”, “You got this!”, “Good luck”, “I hope you feel better”, and “Please help me”, “I’m scared”, “Glad I’m not alone.” *Comparison with other members* involved comparing their feelings, symptoms, situation, etc. to others and often involved words. Examples of this include: “I have that too”, “I’m the same way”, “I know how you feel”, and “Does anyone else...?” *Helping others* involved giving advice to others such as, “Talk to a doctor about it. Study your life and live for something better, something new. Tell yourself that you’ll overcome it.”, “Get a notebook and write down everything you know about your anxiety and anger and PTSD, write down how it makes you feel and how it has changed your life, explain how much it is affecting you and making you hurt and feel bad.”, and “Try reading a book or magazine until you get tired! Distract your mind and hopefully you’ll feel better!” Finally, *sharing experiences* involved sharing personal experiences about themselves, about their situation, about their anxiety.

Examples of this include: “I have 3 friends who swear by it. I've been put on a low dose of hormone birth control pill. One month down & I do feel a little better.”, “I have completely stopped driving for 3 years now, and mine is just not even 5 miles away- I can't even think about getting on the freeway.”, and “Sweetie my daughter is 8 months old and I've had absolutely horrible anxiety since I had her.”

The empowerment outcomes included *feeling informed, increased confidence with physician, increased acceptance, increased optimism and hope for the future, enhanced self-esteem, and enhanced social well-being, and increased confidence in the treatment* (see Table 4). Those outcomes expressed most frequently were *increased acceptance, increased social well-being, and increased optimism and hope for the future*. In the Main Posts, *increased optimism and hope for the future* was expressed most frequently; in the Comment Posts, *increased acceptance* and *increased social well-being* were expressed most frequently.

**Table 4. Codes of Empowerment Outcomes**

<b>Empowerment Outcomes</b>	<b>Main Posts</b>	<b>Outcome / Main Posts (%)</b>	<b>Comment Posts</b>	<b>Outcome / Comments Posts (%)</b>	<b>Total Posts</b>	<b>Outcome / Total Posts (%)</b>
Feeling informed	8	6.2%	101	10.23%	109	9.8%
Increased confidence in physician	7	5.4%	124	12.6%	131	11.8%
Increased acceptance	26	20.2%	196	20.0%	222	19.9%
Increased optimism and hope for the future	39	30.2%	156	15.9%	195	17.5%
Increased self-esteem	21	16.3%	70	7.1%	91	8.2%
Increased social well-being	28	21.7%	177	18.0%	205	18.4%
Increased confidence in treatment	0	0.0%	160	16.3%	160	14.4%
<b>TOTAL</b>	<b>129</b>	<b>100.0%</b>	<b>984</b>	<b>100.0%</b>	<b>1113</b>	<b>100.0%</b>



The proportion of posts that included empowerment outcomes was fewer than with the empowerment processes. *Increased optimism and hope for the future* was the highest in the Main Posts at 5.0%; *increased acceptance* was the highest in the Comment Posts at 5.5%, and was also the highest overall at 5.1% in the Total Posts. These empowerment outcomes were most evident when expressed by users in gratitude to another user or to support another user. With the exception of *increased optimism and hope for the future* and *increased-self-esteem*, the proportion of empowerment outcomes increased from the Main Posts to the Comment Posts. An analysis by user is shown in Appendix III.

**Table 5. Proportion of posts including expressions of empowerment outcomes**

	Main posts	Comment Posts	Total Posts
Feeling informed	1.0%	2.8%	2.5%
Increased confidence in physician	0.9%	3.5%	3.0%
Increased acceptance	3.3%	5.5%	5.1%
Increased optimism and hope for the future	5.0%	4.4%	4.5%
Increased self-esteem	2.7%	2.0%	2.1%
Increased social well-being	3.6%	5.0%	4.7%
Increased confidence in treatment	0.0%	4.5%	3.7%
Total number of posts	782	3585	4367

Note: The percentages are calculated using the frequencies from Table 4 as the numerator and the Total number of posts from this table as the denominator.

*Increased optimism and hope for the future* was the empowerment outcome that occurred most frequently in the Main Posts at 5.0%, while *increased acceptance*, closely followed by *social well-being*, was the empowerment outcome that occurred most frequently in the Comment Posts at 5.5% and 5.0%. *Feeling informed* involved feeling informed from giving advice or feeling informed from receiving advice. Examples of this include: “I’ve just read up on breathing exercises...you’re not dying, it’s just anxiety”, “Love this response...Makes perfect sense”, and “Thank you for your

advice...I will look into it.” *Increased confidence with physician* involved increased confidence with or willingness to see a physician, therapist, etc. Examples of this include: “I will definitely talk to my doctor about the citalopram”, “It's really not as scary as you think... You'll be ok and most probably feel better just by seeing someone”, “My therapist told me about ...I can tell a difference all ready”, and “Go to the doctor if your concerned to put your mind at ease.” *Increased acceptance* involved acceptance with their situation or their feelings over anxiety. Examples of this include: “I feel content and life's manageable again”, “It's all in our heads”, “Once you start realizing that everything you feel is due to anxiety things will be so much easier... I am doing much better now & just know that things will go back to normal” and “I try not to worry about the bad days and try to look positive for the good.” *Increased optimism and hope for the future* involved feelings of positivity for the future. Examples of this include: “Positive attitude will be positive results!” and “there's light at the end of the tunnel”. *Enhanced self-esteem* involved some kind of positive feelings about themselves or their situation, often from a success or from social support. Examples of this include: “I did really good today!”, “I have recovered from hypochondria!”, “I'm crying because of how happy your comments have made me”, and “Having you relate will help me have a brighter day.” *Enhanced social well-being* involved feelings of being a part of the online health community. Examples of this include: “This forum makes me feel better most of the times...great people”, “It's comforting seeing I'm not the only one”, “You aren't alone.”, and “It feels so good to be understood.” Finally, *increased confidence in treatment* involved greater confidence in medication, lifestyle modifications, alternative medicine, etc. Examples of this include: “I started my meds today and hoping and praying for a

good course of action”, “if you need to take a tablet a day to feel better than so be it”, and “GABA and Rescue Remedy has helped me.”

There were 215 multiple, repeat posters in the online forum discussion group. Forty only commented on others’ Main Posts, while the other 175 both commented and posted. The majority of these were patients and fellow sufferers of anxiety. However, there were two that could be confirmed as community managers or advocates. One user, #68, was a self-professed health professional whose username included the prefix “Dr.” He was included under the “What Our Advocates Are Saying” section and is thus verifiable as a community advocate. Another user, #90, was identified as a community advocate or community manager due to the administrative content of the user posts. The latter is not a current community manager but was in the 2014 three-month data.

## Discussion

The findings of this study were consistent with other previous studies. This included that patient empowerment was present in online health communities, particularly the empowerment processes, and that interacting with other members in online health communities facilitated patient empowerment. Both Bartlett and Coulson (2011) and van Uden-Kraan et al. (2009) found that participating in online communities increased patient empowerment.

In this study, patient empowerment processes were evident in every single post. There were 7162 patient empowerment processes present in the 4367 Total Posts. The empowerment process with the greatest presence was *sharing experiences*, expressed 2515 times in 57.6% of Total Posts, and in 87.0% of the Main Posts. *Exchanging social* support was also a very important factor, appearing 1710 times in 39.2% of Total Posts, and in 40.6% of the Comment Posts. The empowerment process that was much less frequent in the Main Posts was *helping others*, appearing only 723 times overall, in 16.6% of Total Posts, but only 3.71% of Main Posts. Possible explanations of these highs and lows lie in the nature of online health communities being highly personal and interactive in a non-clinical manner. Members of the community wanted to interact on a personal level and therefore the empowerment processes that involved sharing of their personal experiences or emotions occurred more frequently. *Helping others* appeared very infrequently in Main Posts, but increased in the Comment Posts due to members answering other community members' questions in a practical manner.

In comparison, patient empowerment outcomes were present but less evident in the forum posts. There were 1113 patient empowerment outcomes expressed in 723 posts (out of 4367 Total Posts). In this group discussion forum, only 16.6% of the posts included an indication of an empowerment outcome. The most prevalent empowerment outcome was *increased acceptance*, occurring 222 times in 5.1% of Total Posts. *Optimism and hope for the future* and *increased social well-being* also occurred frequently (195 and 205 times, respectively) in 4.5% and 4.7% of the Total Posts, respectively. Although not as high, *increased confidence in the physician* and *increased confidence in the treatment* were also important outcomes in the community, appearing 131 and 160 times, respectively, in 3.0% and 3.7% of the Total Posts, respectively. From the forum posts the patients received a lot of reassurance about different medical professionals, about different medications (particularly symptoms of medications), about alternative methods, and about life-style modifications. Particularly in a mental health area where there is a lot of stigma associated with taking medication (Eisenberg et al., 2009), these outcomes were present in more posts than expected.

The length of posts often indicated how many processes were involved in it. Short posts of several words to one sentence usually included only one process. Longer posts of at least several sentences usually included two to four processes. The shorter posts present an empowerment process through the act of responding to a post; all of the shorter posts were included within the Comment Posts. The empowerment processes present in these short posts were predominantly *exchanging information* or *exchanging social support*, which is consistent with the prevalence of the two processes overall.

It was observed while coding that certain empowerment processes often were present together in the same post, as were pairs of certain empowerment outcomes. *Exchanging information* was often paired with *helping others*. *Sharing experiences* was often paired with either *comparison with others* or *exchanging support*. Other combinations did exist but these occurred most frequently. For empowerment outcomes, a common pairing was *increased acceptance* and *increased optimism and hope for the future*.

In this time period (early 2014), Anxiety Connect was a highly active, online health community, with 215 repeat, multiple posters. Of those, 213 were patients and 2 were community advocates. Information utility, social support, high level of activity, community engagement, and moderation were all elements of online health communities related to patient empowerment mentioned in the Johnston et al. (2013) study, and were present in the current study and Anxiety Connect at the time the forum data occurred. The moderators were not viewable in the same manner for this study as for Johnston et al. Viewable in Anxiety Connect are the two community advocates and their roles based on their forum posts. User #90 was a community manager and had an administrative role in the community. User #90's six posts were strictly exchanging information about the online health community and exchanging brief social support of welcoming members to the online health community. Some of the content #90 expressed was in regards to the shutdown of the support of the mobile application. After seeing the high level of activity and patient empowerment success of this period compared to the less active group discussion forum currently available, this shutdown decision could be viewed as a mistake. A mobile application would allow Anxiety Connect to be brought anywhere and

all the time with the patient and many of the forum posts expressed an urgent need for an immediate or at least quick response. Considering the nature of anxiety as a mental health illness and the constant need for support and community expressed in the forum posts, it can be inferred that the community activity decreased due to a decrease in ways to access the forum. User #68 was a community advocate and a self-reported psychiatrist. User #68 posted a lot more frequently than #90, for a total of 56 empowerment processes and 12 empowerment outcomes expressed within 28 posts. User #68 mimicked the personal interaction of community members with *exchanging social support* and *helping others* in addition to *exchanging information*. As #68 was not a fellow sufferer of anxiety, *comparison with others* and *sharing experiences* could not be expressed but the addition of the previously stated empowerment processes gave a warmth to the posts addressing community members and allowed user #68 to be included within the community.

## Conclusion

In conclusion, Anxiety Connect, a moderated online health community for patients with anxiety, did present both patient empowerment processes and outcomes in the group discussion forum. The empowerment processes were present in every post to the forum. The empowerment outcomes were not as plentiful but were present. The mere act of posting guaranteed that an empowerment process was occurring and the longer the post, the more likely that multiple empowerment processes were occurring. This trend was possibly due to a higher level of engagement.

There were limitations in this study's methods that should be taken into account when interpreting the findings. While moderation was of interest in this study, moderator actions could not be examined directly due to not being able to gain access to a non-moderated site to potentially compare results between online health communities. The actions of the moderator may include deleted posts or private messages to users not available in an archive of posts. This study was only able to report on what was viewable in the posts and, as noted in the literature review, there are lurkers in online forums who do not post but only lurk. In addition, seven users and 22 individual posts should not have been included based on selection criteria, due to only 3 to 4 posts each, but were missed in the initial data cleanup. Thus, the final data set, while representative of activity in this forum, did not take into account the effects of moderation and the benefits potentially received by lurkers.



The method of coding the forum posts to measure the empowerment processes was successful. This study is the first study, to the best of my knowledge, to use an archive of forum posts to study patient empowerment. Other researchers used a quantifiable method as well in the form of questionnaires, but the current study used naturally occurring data. Both Bartlett and Coulson (2011) and van Uden-Kraan et al. (2009) used patient questionnaires to gather data on the presence of patient empowerment, which was self-reported data and could have varied depending on each patient's perception of the five point scale. The current study also focused on the individual forum posts rather than the patients' impressions of the online health community as a whole. The patient empowerment processes were strengthened by this method and were expressed in every post, while the patient empowerment outcomes were not as complete in this data. This does not mean that the empowerment outcomes were not present in the community but more likely that the patients did not feel the need to express them in the forum posts every time. Recommendations for future research would include using this method to measure the processes in combination with using a questionnaire, if access to the patients is available, to measure the empowerment outcomes.

Based on the findings there are several recommendations for the Anxiety Connect site, the moderators and patients of the online health communities. For patients, the investigator recommends the use of online health communities based on the findings of the study. Participation in the community increased patient empowerment and reinforced healthy ways of coping with the mental health illness that could not be gained from doctor visits alone. For moderators, the investigator recommends following the example

of user #68 who mimicked the interaction style of the patients with higher usage of the empowerment processes, *exchanging social support* and *helping others*. User #68 played a unique role in the community but was also more incorporated into the community than user #90. For the Anxiety Connect site, the investigator recommends re-implementing a mobile application version of the online health community. Mobile smartphone ownership has increased greatly and the community members have shown a desire to have greater access at all times. With greater access to Anxiety Connect, higher usage and higher interaction activity would allow for greater patient empowerment.

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# Appendices

## I. Coding Manual

### Patient Empowerment Processes

*Exchanging Information:* Giving or asking for factual information; eg. Drug information, anxiety information, treatment information

*Exchanging Social Support:* Giving or asking for emotional support, includes exchanging instant messaging information to facilitate emotional support; eg. Help me, I'm scared, kik username, We're here for you, etc.

*Comparison With Others:* Giving or asking for comparison with other group members; eg. I'm having \_\_\_\_ symptom. Has anyone else had it too?, You sound just like me, I have this as well, etc.

*Helping Others:* Giving practical advice, often involving steps to do something; eg. Take a deep breath, take a sip of water, write down your thoughts to distract yourself.

*Sharing Experiences:* Personal experiences or stories about themselves; eg. I have two children and my anxiety started after I had them.

### Patient Empowerment Outcomes

*Feeling Informed:* Having a sense of greater knowledge than before; eg. I read this great book and it helped me a lot.

*Increased Confidence in Physician:* Recommending a physician or deciding to see a physician; eg. I will talk to my therapist about the medication.

*Increased Acceptance:* Feelings of acceptance towards anxiety or their situation; eg. It is because of anxiety but I will take it day by day.

*Increased Optimism and Hope for the Future:* Talk of the future associated with feelings of hope; eg. We are survivors! We will do make it one day at a time!

*Increased Self-Esteem:* Better perceptions of self or more positive feelings associated with self; eg. I did really good today!

*Increased Social Well-being:* Talk of their social sphere or the online health community being a community; eg. It has helped me so much that everyone in the community is so supportive.

*Increased Confidence in Treatment:* Greater confidence in a treatment such as medication, lifestyle modification or alternative medicine; eg. If you need to take a tablet a day than so be it.

## II. User Data: Empowerment Processes

User	# of Posts with Empowerment Processes	# of Process Codes of Each Type				
		Exchanging information	Exchanging social support	Comparison with others	Helping Others	Sharing Experiences
1	9	1	6	4	2	4
2	30	10	11	13	1	20
3	16	9	5	1	8	8
4	33	4	6	16	0	25
5	17	12	2	6	9	5
6	11	5	6	4	9	5
7	21	2	11	7	7	14
8	13	4	5	0	0	6
9	7	1	3	2	0	6
10	10	2	6	1	3	7
11	15	4	6	6	2	10
12	12	2	4	6	1	9
13	29	10	8	6	9	15
14	15	4	6	5	5	8
15	8	2	2	1	3	7
16	5	1	1	1	1	4
17	10	3	2	0	6	2
18	48	14	7	17	10	33
19	11	2	2	0	1	11
20	24	4	12	6	2	10
21	14	5	4	4	0	8
22	7	3	2	1	0	6
23	17	5	3	6	5	9
24	3	1	1	0	0	1
25	5	1	2	4	0	4
26	14	1	9	0	0	10
27	45	5	17	15	4	26
28	17	4	6	5	2	10
29	18	3	6	6	5	14
30	9	3	3	3	4	6
31	69	20	27	15	7	37
32	13	5	4	1	1	7
33	10	4	5	3	5	9
34	6	1	1	0	0	5
35	7	0	6	1	0	5
36	12	3	10	3	0	4
37	5	2	1	0	0	3

User	# of Posts with Empowerment Processes	# of Process Codes of Each Type				
		Exchanging information	Exchanging social support	Comparison with others	Helping Others	Sharing Experiences
38	15	4	3	4	1	8
39	41	8	11	14	2	13
40	3	0	1	0	1	1
41	11	8	2	1	1	2
42	12	5	4	3	1	7
43	7	1	3	2	0	4
44	17	2	11	4	1	9
45	8	2	6	2	3	4
46	14	2	9	3	0	7
47	10	4	3	1	0	2
48	15	2	10	5	3	11
49	23	4	10	6	6	16
50	11	4	4	3	1	8
51	10	1	0	3	2	8
52	7	1	3	4	0	7
53	31	6	9	6	1	22
54	11	1	3	2	4	6
55	14	2	5	6	0	10
56	33	6	10	1	0	25
57	12	2	8	4	4	5
58	16	3	7	3	1	10
59	19	5	9	7	0	6
60	53	24	23	9	11	22
61	34	4	7	11	1	28
62	18	4	7	5	8	10
63	11	0	4	3	1	10
64	134	38	30	47	12	94
65	5	2	1	0	0	2
66	9	2	6	3	1	5
67	13	5	1	2	7	8
68	28	11	22	2	15	6
69	47	13	19	14	12	27
70	13	3	6	6	1	4
71	29	5	15	5	2	9
72	17	2	2	5	2	14
73	5	0	4	0	0	2
74	52	17	8	23	1	37
75	7	5	1	2	1	4
76	17	4	4	6	0	11

User	# of Posts with Empowerment Processes	# of Process Codes of Each Type				
		Exchanging information	Exchanging social support	Comparison with others	Helping Others	Sharing Experiences
77	6	2	2	3	1	1
78	7	1	6	0	0	5
79	9	1	5	4	0	3
80	9	2	6	1	3	5
81	5	0	2	1	0	3
82	16	3	7	5	1	14
83	18	0	7	6	2	12
84	6	6	1	1	4	3
85	15	3	5	4	1	6
86	5	2	2	0	1	4
87	33	12	8	7	10	13
88	6	0	5	0	0	5
89	12	4	5	2	4	6
90	6	4	1	0	0	0
91	6	1	0	3	1	2
92	30	9	14	5	8	14
93	45	15	17	13	7	28
94	5	0	1	3	0	5
95	18	3	6	2	1	9
96	7	1	3	2	2	5
97	11	4	3	4	4	6
98	8	2	4	2	0	5
99	14	1	9	2	1	10
100	31	9	5	11	3	23
101	3	0	1	2	0	2
102	10	1	3	2	0	7
103	19	7	9	5	7	7
104	8	0	0	3	0	8
105	33	10	23	7	10	13
106	6	2	3	6	1	5
107	14	5	11	2	8	5
108	3	1	1	1	1	2
109	20	3	9	7	2	18
110	30	11	16	5	2	13
111	39	12	16	5	5	17
112	33	4	16	1	2	15
113	5	2	2	1	0	3
114	35	8	12	8	7	25
115	9	2	4	3	1	4

User	# of Posts with Empowerment Processes	# of Process Codes of Each Type				
		Exchanging information	Exchanging social support	Comparison with others	Helping Others	Sharing Experiences
116	7	0	2	3	2	6
117	3	0	0	0	0	3
118	20	4	4	6	1	16
119	5	0	2	0	0	4
120	57	18	29	10	20	25
121	39	3	8	12	1	30
122	18	6	7	4	4	8
123	56	13	18	7	11	31
124	28	9	7	11	2	18
125	5	0	1	0	0	5
126	16	1	5	5	6	13
127	100	16	73	13	12	36
128	8	1	5	4	3	3
129	65	20	24	15	4	40
130	41	13	14	8	0	13
131	32	4	15	11	9	22
132	33	11	7	7	1	23
133	5	1	0	3	2	4
134	6	1	2	2	1	2
135	5	0	3	1	2	2
136	10	1	5	0	4	2
137	32	16	14	1	3	9
138	17	2	12	6	0	13
139	18	9	4	8	4	11
140	6	1	5	0	0	2
141	7	2	4	0	0	6
142	8	0	3	2	1	6
143	7	2	5	1	2	3
144	9	1	2	6	1	6
145	7	1	1	2	1	5
146	75	31	46	18	32	23
147	21	2	11	6	1	18
148	7	2	3	5	3	4
149	37	4	21	12	0	26
150	5	2	1	1	0	4
151	17	5	10	5	4	9
152	8	5	4	1	1	2
153	12	8	3	2	6	7
154	24	2	16	5	4	11



User	# of Posts with Empowerment Processes	# of Process Codes of Each Type				
		Exchanging information	Exchanging social support	Comparison with others	Helping Others	Sharing Experiences
155	24	7	6	10	3	17
156	41	9	19	12	7	27
157	40	9	15	11	7	26
158	4	3	1	0	4	1
159	10	7	0	0	1	3
160	7	0	2	5	1	6
161	11	2	3	3	1	9
162	28	7	10	1	7	8
163	10	1	4	3	0	7
164	14	5	6	6	0	10
165	30	4	11	6	12	19
166	20	2	15	2	0	5
167	23	6	13	10	1	14
168	12	2	5	6	2	6
169	54	30	22	8	27	14
170	55	11	30	8	18	37
171	14	4	4	2	2	7
172	13	5	2	1	2	6
173	7	0	3	1	0	5
174	3	0	2	0	1	1
175	6	3	2	1	0	2
176	136	42	18	47	18	103
177	8	2	0	4	0	6
178	53	7	27	14	5	25
179	12	7	3	0	1	3
180	16	5	8	6	2	8
181	5	2	2	2	0	3
182	15	1	9	4	1	9
183	42	19	11	10	8	21
184	7	0	5	0	0	4
185	21	2	13	3	0	15
186	9	2	3	3	1	4
187	14	4	4	1	1	10
188	57	13	25	16	10	42
189	72	34	23	10	42	42
190	10	2	4	1	6	5
191	5	1	4	3	1	0
192	6	3	1	3	0	2
193	8	1	3	5	0	8

User	# of Posts with Empowerment Processes	# of Process Codes of Each Type				
		Exchanging information	Exchanging social support	Comparison with others	Helping Others	Sharing Experiences
194	17	0	7	4	1	12
195	28	6	23	6	11	13
196	12	5	2	2	5	5
197	47	13	23	19	2	30
198	14	2	12	3	1	4
199	17	7	7	2	4	6
200	24	5	8	7	2	17
201	24	5	7	5	0	21
202	17	5	2	3	10	12
203	6	1	3	0	4	2
204	8	0	3	1	1	7
205	53	13	14	12	4	33
206	106	13	55	33	5	61
207	14	5	3	4	1	7
208	22	7	12	5	0	6
209	13	7	4	2	1	3
210	8	2	3	2	0	4
211	12	3	3	5	3	8
212	26	5	4	3	3	19
213	24	4	4	5	4	16
214	29	3	14	5	2	24
215	6	2	4	0	0	5
<b>Totals</b>	4367	1120	1710	1094	723	2514

### III. User data: Empowerment Outcomes

User	Posts with Empowerment Outcomes	# of Outcome Codes of Each Type						
		Feeling informed	Increased confidence in physician	Increased acceptance	Increased optimism and hope for the future	Increased self-esteem	Increased social well-being	Increased confidence in treatment
1	2	1	0	0	1	0	1	0
2	3	0	0	1	0	0	2	0
3	6	0	0	1	3	1	3	2
4	1	0	0	0	0	0	1	0
5	5	0	0	1	1	1	0	1
6	3	0	1	1	2	1	2	1
7	12	0	2	0	5	6	0	2
8	0	0	0	0	0	0	0	0
9	0	0	0	0	0	0	0	0
10	4	0	2	1	0	0	1	0
11	4	1	0	1	2	1	0	0
12	1	0	0	1	0	0	0	0
13	7	0	0	4	5	2	2	0
14	2	1	0	1	0	0	1	4
15	1	0	0	1	1	0	0	0
16	2	1	1	0	0	0	0	0
17	2	0	1	0	0	0	1	2
18	8	1	4	3	3	0	0	1
19	0	0	0	0	0	0	0	0
20	1	1	0	0	0	0	0	0
21	2	0	1	0	0	0	0	2
22	0	0	0	0	0	0	0	0
23	3	0	2	1	1	0	0	0
24	0	0	0	0	0	0	0	0
25	0	0	0	0	0	0	0	0
26	0	0	0	0	0	0	0	0
27	2	2	0	0	0	0	0	3
28	2	0	0	1	2	0	1	0
29	5	1	1	2	0	1	2	1
30	1	0	0	0	0	1	1	1
31	8	1	4	2	1	0	0	4
32	7	2	1	4	2	1	2	0
33	5	0	0	2	1	0	3	0
34	0	0	0	0	0	0	0	0
35	0	0	0	0	0	0	0	0

User	Posts with Empowerment Outcomes	# of Outcome Codes of Each Type						
		Feeling informed	Increased confidence in physician	Increased acceptance	Increased optimism and hope for the future	Increased self-esteem	Increased social well-being	Increased confidence in treatment
36	1	0	0	0	0	0	1	0
37	1	0	0	0	0	0	1	1
38	2	0	2	0	0	0	0	0
39	4	0	1	1	2	0	0	2
40	0	0	0	0	0	0	0	0
41	0	0	0	0	0	0	0	1
42	3	1	0	2	2	1	0	0
43	0	0	0	0	0	0	0	0
44	3	0	0	2	1	1	1	0
45	3	0	3	0	0	0	0	0
46	4	0	0	1	0	1	4	0
47	1	1	0	0	0	0	0	0
48	3	0	0	1	2	1	2	1
49	7	1	2	3	2	1	1	2
50	2	2	0	0	0	0	0	0
51	0	0	0	0	0	0	0	0
52	4	0	0	3	2	1	0	0
53	2	1	0	0	1	0	0	2
54	2	0	1	0	0	0	0	0
55	4	0	0	0	0	0	3	0
56	3	1	0	0	1	0	2	1
57	2	0	1	1	1	1	2	1
58	4	1	0	3	1	4	3	0
59	0	0	0	0	0	0	0	0
60	8	5	0	1	2	0	1	0
61	0	0	0	0	0	0	0	0
62	2	0	0	1	1	1	0	0
63	4	0	0	1	1	0	2	0
64	17	1	5	3	2	5	3	10
65	1	0	0	0	0	0	1	0
66	3	1	0	0	3	0	1	0
67	5	1	0	2	3	0	1	1
68	6	1	3	2	2	1	1	2
69	6	0	0	5	1	2	0	2
70	0	0	0	0	0	0	0	0
71	2	0	2	0	0	0	0	2
72	4	0	0	2	2	1	2	0

User	Posts with Empowerment Outcomes	# of Outcome Codes of Each Type						
		Feeling informed	Increased confidence in physician	Increased acceptance	Increased optimism and hope for the future	Increased self-esteem	Increased social well-being	Increased confidence in treatment
73	0	0	0	0	0	0	0	0
74	3	0	0	1	2	0	2	2
75	0	0	0	0	0	0	0	0
76	0	0	0	0	0	0	0	0
77	2	0	1	0	0	1	1	0
78	0	0	0	0	0	0	0	0
79	0	0	0	0	0	0	0	0
80	6	0	0	0	0	1	5	2
81	1	0	0	0	1	0	1	0
82	6	1	1	3	3	1	1	0
83	2	0	0	2	0	0	0	0
84	0	0	0	0	0	0	0	0
85	3	0	1	0	2	0	0	1
86	1	0	0	0	0	0	0	1
87	4	0	0	4	0	0	0	1
88	1	0	0	1	1	0	0	0
89	6	1	2	4	2	0	1	2
90	0	0	0	0	0	0	0	0
91	0	0	0	0	0	0	0	0
92	1	0	0	0	1	0	1	2
93	10	0	6	2	1	1	2	2
94	0	0	0	0	0	0	0	0
95	0	0	0	0	0	0	0	1
96	1	0	0	1	0	0	0	1
97	1	0	0	0	1	1	0	1
98	0	0	0	0	0	0	0	0
99	4	0	0	1	0	0	3	2
100	7	3	1	2	1	0	3	0
101	0	0	0	0	0	0	0	0
102	3	0	0	1	0	0	2	0
103	7	3	1	1	3	0	1	1
104	1	0	0	0	0	0	1	1
105	9	1	0	0	3	1	5	0
106	2	0	0	2	0	0	0	0
107	4	2	1	1	0	1	0	0
108	1	0	0	1	0	0	0	0
109	5	0	1	2	1	1	2	0

User	Posts with Empowerment Outcomes	# of Outcome Codes of Each Type						
		Feeling informed	Increased confidence in physician	Increased acceptance	Increased optimism and hope for the future	Increased self-esteem	Increased social well-being	Increased confidence in treatment
110	3	1	1	0	0	0	0	2
111	5	0	0	2	5	2	3	1
112	1	1	0	0	0	0	0	3
113	0	0	0	0	0	0	0	0
114	7	0	3	4	1	0	0	3
115	2	0	0	2	0	0	0	0
116	3	0	0	2	1	0	1	0
117	1	0	0	0	1	1	0	0
118	3	2	0	0	1	0	0	1
119	1	0	0	1	1	0	0	0
120	13	2	2	1	4	3	3	3
121	3	0	2	1	1	0	0	0
122	3	1	0	0	0	0	0	1
123	8	1	3	3	0	0	2	1
124	6	3	1	2	2	0	1	0
125	1	0	1	1	0	0	0	0
126	5	1	2	0	0	0	1	0
127	22	4	0	5	7	7	6	8
128	2	0	0	1	0	0	0	2
129	12	1	1	5	3	2	2	6
130	0	0	0	0	0	0	0	2
131	7	1	1	3	5	2	3	2
132	5	0	3	0	0	0	0	1
133	0	0	0	0	0	0	0	0
134	2	0	0	0	0	1	2	0
135	1	0	0	1	0	0	0	1
136	0	0	0	0	0	0	0	0
137	3	1	0	1	0	1	1	1
138	2	0	0	0	0	1	2	0
139	3	1	0	1	2	0	0	0
140	0	0	0	0	0	0	0	0
141	0	0	0	0	0	0	0	0
142	0	0	0	0	0	0	0	1
143	2	1	0	1	0	0	0	0
144	1	0	0	1	0	0	0	1
145	0	0	0	0	0	0	0	0
146	8	2	0	3	4	2	1	5

User	Posts with Empowerment Outcomes	# of Outcome Codes of Each Type						
		Feeling informed	Increased confidence in physician	Increased acceptance	Increased optimism and hope for the future	Increased self-esteem	Increased social well-being	Increased confidence in treatment
147	5	0	2	3	1	0	1	0
148	0	0	0	1	1	0	0	1
149	4	2	0	1	0	0	1	1
150	0	0	0	0	0	0	0	1
151	5	1	1	1	1	0	3	1
152	3	1	1	0	0	0	2	0
153	3	0	1	0	1	0	0	0
154	9	2	0	5	2	2	6	0
155	4	0	1	2	0	0	0	1
156	18	5	5	6	2	2	9	1
157	11	3	1	1	3	1	2	0
158	0	0	0	0	0	0	0	0
159	0	0	0	0	0	0	0	0
160	0	0	0	0	0	0	0	0
161	4	1	0	0	1	1	1	0
162	2	0	1	1	0	0	0	1
163	2	0	0	0	1	0	2	3
164	1	0	0	1	0	0	0	1
165	7	0	1	2	2	0	3	1
166	1	0	0	0	1	0	0	2
167	5	0	0	0	2	1	4	1
168	1	0	0	0	1	0	0	0
169	13	3	3	0	2	1	2	4
170	15	2	0	8	3	1	8	2
171	2	0	0	1	1	0	0	0
172	0	0	0	0	0	0	0	0
173	0	0	0	1	0	0	0	1
174	0	0	0	0	0	0	0	0
175	0	0	0	0	0	0	0	0
176	8	2	5	1	2	0	2	6
177	0	0	0	0	0	0	0	0
178	5	0	0	0	0	0	5	1
179	2	0	0	0	0	0	0	0
180	3	0	1	0	1	1	2	2
181	0	0	0	0	0	0	0	0
182	0	0	0	0	0	0	1	0
183	4	1	1	1	3	0	0	0

User	Posts with Empowerment Outcomes	# of Outcome Codes of Each Type						
		Feeling informed	Increased confidence in physician	Increased acceptance	Increased optimism and hope for the future	Increased self-esteem	Increased social well-being	Increased confidence in treatment
184	0	0	0	0	0	0	0	0
185	1	0	0	0	0	0	1	0
186	1	1	0	1	0	0	0	0
187	1	0	0	0	0	1	1	2
188	13	2	4	3	5	1	6	0
189	30	7	8	16	9	1	4	4
190	4	0	2	0	1	0	0	0
191	1	0	1	0	0	0	0	0
192	1	0	0	1	0	1	1	0
193	0	0	0	0	0	0	1	0
194	4	1	0	2	1	1	1	0
195	5	0	0	1	3	0	2	1
196	0	0	0	0	0	0	0	0
197	10	0	2	2	1	0	1	1
198	2	0	1	0	0	0	1	0
199	5	0	2	1	3	1	1	0
200	10	5	3	2	4	0	0	0
201	2	0	0	1	1	1	1	1
202	10	2	2	3	3	2	4	0
203	2	0	0	2	2	0	0	0
204	0	0	0	0	0	0	0	0
205	6	0	0	3	0	1	3	0
206	20	1	2	8	2	1	6	2
207	2	1	0	1	0	0	0	0
208	3	0	0	2	2	0	0	0
209	0	0	0	0	0	0	0	0
210	0	0	0	0	0	0	0	0
211	5	1	1	1	2	2	3	0
212	1	2	0	1	1	0	0	0
213	5	0	1	2	2	2	0	0
214	4	0	3	1	0	0	0	0
215	0	0	0	0	0	0	0	0
Totals	723	109	131	222	195	91	205	160